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THE DEVELOPMENT OF SERVICES FOR MENTALLY RETARDED CHILDREN AND YOUTH IN RURAL AREAS.

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THIS PAPER PRESENTS INFORMATION ON THE NEED FOR THE DEVELOPMENT OF A VARIETY OF ADDITIONAL SERVICES TO ENABLE OUT-OF-SCHOOL, UNEMPLOYED, RETARDED YOUTH TO BECOME BETTER PREPARED FOR THEIR RESPONSIBILITIES TO THE COMMUNITY. DIFFERENT GROUPS OF RETARDED PERSONS ARE DISCUSSED, AND A RATIONALE FOR NEEDED SERVICES IS SUGGESTED. REPORTS FROM 19 STATES AND THE DISTRICT OF COLUMBIA ARE USED TO DESCRIBE PROGRAMS AND PROGRAM GOALS FOR RURAL YOUTH. THE THREE MAJOR PROBLEMS THAT MUST BE SQUARELY FACED TO EXPEDITE LOCAL PROGRAMS AND SERVICES ARE--TRANSPORTATION, FACILITIES WITH RESIDENTIAL CENTERS, AND QUALIFIED STAFF TO MAN THE PROGRAMS. RECOMMENDATIONS MADE FOR ORGANIZING LOCAL ACTION INCLUDE THE NEED FOR MOBILE RESIDENTIAL UNITS, MORE CREATIVE USE OF EXISTING FACILITIES, INCREASES IN VOLUNTARY AND GOVERNMENTAL RESOURCES, MORE PILOT PROJECTS, AND A NEW APPROACH TO THE ESTABLISHMENT OF RURAL PEACE CORPS. THIS PAPER WAS PREPARED FOR PRESENTATION AT THE NATIONAL CONFERENCE ON PROBLEMS OF RURAL YOUTH IN A CHANGING ENVIRONMENT (SEPTEMBER 1963). (AUTHOR)

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ABSTRACT

THE DEVELOPMENT OF SERVICES FOR MENTALLY RETARDED CHILDREN AND YOUTH IN RURAL AREAS

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This paper presents information on the need for the development of a variety of additional services to enable out of school, unemployed, retarded youth to become better prepared for their responsibilities to the community. Different groups of retarded persons are discussed and a rationale for needed services is suggested. Reports from 19 states and the District of Columbia are used to describe programs and program goals for rural youth. The three major problems that must be squarely faced to expedite local programs and services are: transportation, facilities with residential centers, and qualified staff to man the programs. Recommendations made for organizing local action include the need for mobile residential units, more creative use of existing facilities, increases in voluntary and governmental resources, more pilot projects, and a new approach to the establishment of a Rural Peace Corps.

THE DEVELOPMENT OF SERVICES FOR MENTALLY RETARDED CHILDREN AND YOUTH IN RURAL AREAS

One person out of every thousand of the total population or one-tenth of one percent is so retarded as to function on a dependent level requiring hour-by-hour care and supervision. Many have severe physical handicaps, other disabling conditions, are unable to walk or to talk, and must be fed and clothed. Yet, some of these individuals have responded to training in basic self-care. These efforts, when successful, decrease the need for dependence and enrich an individual's human existence to the point that he can care for his bodily needs and learn to walk, speak, dress, and feed himself.

Four persons out of every thousand or four-tenths of one percent are in a middle group and function on a semi-dependent level. Those in the upper level of this group develop socially and intellectually at less than half the rate of the average person. Many have capabilities for learning essential skills for daily living, acquire patterns of acceptable social behavior, and can perform useful work. As children they are considered "trainable" and are able to profit from an essentially nonacademic curriculum in special classes which prepare them to achieve their potentials for later economic and social usefulness. When they are provided extensive job evaluations and job training, a number are able to achieve productive roles within sheltered environments. A few have eventually gone into competitive employment.

Twenty-five persons out of every thousand or two and one-half percent function on a marginal-independent level. Individuals in the upper levels of this group develop at less than three-fourths the social and intellectual rate of the average person. As children they are considered "educable" and able to profit from attendance at special classes which prepare them to participate in community life with a minimum of supervision. When provided with occupational information and assistance in job placement, they are able to work in unskilled and semi-skilled jobs. Many eventually become self-supporting adults capable of managing their own affairs but may require counseling in periods of stress and crisis. Others are able to work and partially support themselves.

RATIONALE FOR SERVICES

How can every rural village, town, county, city and state provide the necessary "total program" and services needed for retarded persons and their families? Everywhere there can be seen the vast numbers to be served, the general lack of qualified personnel, the need for more adequate facilities, the necessity for greater financial support for such programs, the unevenness of programs and services around the nation with some parts of the country more advanced than others, and an overall uninformed general public regarding the need such retardates have for urgently needed services. What needs to be done?

Today it is becoming less important to classify the mentally retarded, as compared with understanding the range of programs and services different kinds of retardates may require. No matter how groupings are determined the in-between persons are forever excluded. Some persons seem never to fit into pre-

arranged and ordered schemes. Rather than defend or challenge any classification system, we need to consider instead the retardate. What problems does he pose? What solutions are in the offing?

Each person tends to look upon the retardate differently depending upon his interest, discipline, agency or responsibility to him. To one person he is a patient, to another a pupil, client, trainee, worker, and to still others a son or daughter or a sister or brother. But to all persons he must be thought of primarily as an individual who is in need of varying degrees of help. Some retarded persons require extensive evaluations, long periods of treatment, and considerable training and supervision to attain even the most limited personal and social goals of independence. Others are so minimally retarded as to pass unnoticed in the community. However, during periods of stress and crisis, these persons may require counseling and guidance to maintain a proper balance and continue to remain in the community on their own.

There are a number of persons working with the mentally retarded who feel that one cannot repair or reconstruct or rehabilitate the individual who is mentally retarded. They believe that the mentally retarded require a comprehensive, well planned, interrelated program of services which permit them to achieve their full potential. They recommend habilitation programs begin immediately after the diagnosis mental retardation has been made. Such a view places the focus more on enabling these disabled to function than it does on restoring them functionally. Please note, the term disabled not handicapped was used. Mentally retarded persons are disabled. However, they all need not necessarily become handicapped. For example, they need not become educationally handicapped, socially handicapped or vocationally handicapped, even though they will be limited in these areas. It is generally believed that through habilitation programs one can prevent many mentally retarded persons from becoming community handicaps.

Without question there are times when rehabilitation or restorative services will be required for mentally retarded persons. This occurs when planning programs and services for those mentally retarded persons who have secondary disabling conditions. Some examples are the mentally retarded cerebral palsied, the mentally retarded with epileptic seizure, the mentally retarded deaf, the mentally retarded blind or the mentally retarded with speech impairments. In such instances a partial or full range of physical medicine and rehabilitation services may be indicated.

It is becoming a more accepted viewpoint that the current estimated five and one-half million children and adults in this country believed to be mentally retarded require both rehabilitation and habilitation services. In order to properly provide essential programs and services for this large group of mentally retarded children and adults particularly in rural areas, there is obviously a need for a wide variety of services in the areas of health, education, and welfare.

It appears that there is sufficient knowledge and experience gathered throughout the nation to indicate what might be expected as realistic education and rehabilitation goals for mentally retarded youth and adults. These are, in the main, employment in competitive industry, sheltered employment, community

activity programs, and residential programs. All of these goals can be expected for most retarded youth and adults. However, noticeable differences will be found in the attainment of such goals in the three different functional categories of mentally retarded persons. The majority of such persons will be able to work, a lesser number will achieve sheltered work status, while an even smaller group will profit from community activity programs and services.

The nation faces one major problem that this Conference will give considerable thought to. This is the problem of the 16 to 18 year old and older retardate who is out of school and in need of further education or a rehabilitation service. Few public schools provide any special classes for this age person who either graduates, drops out or is terminated as unable to profit from further education even though legislation is "on the books" for such persons to receive an education to age 21! Few of these youths are considered eligible or feasible for vocational rehabilitation or other services. Consequently this group of retarded youth remain at home or in their local communities with little guidance or direction for their future. To maintain whatever gains they have made through education, as well as to prevent a diminution of function and a subsequent need for retraining, this group requires additional education and/or rehabilitation services. Furthermore, there are some retardates in the 16 to 18 year old range who are employed but who still need rehabilitation services to overcome a personal or social problem they face on the job or at home.

At this point at least two crucial questions might be asked: (1) What type educational or prevocational program will best prepare retarded youth for gainful employment? (2) What other services might be required before or after educational-rehabilitation services to better prepare such retarded youth for competitive work?

DESCRIPTION OF SERVICES

The 1960 White House Conference on Children and Youth Recommendation (582) 1/ appears to supply a partial answer to both these questions. It states:

"That such urgently needed community facilities for the mentally handicapped as the following be developed and improved at an accelerated rate: diagnostic and treatment clinics; public health services; preschool nurseries; day-care centers; special education; avocational and prevocational services; sheltered workshops and other work opportunities; vocational guidance, counseling, habilitation, and rehabilitation services; foster homes, residential treatment centers; recreational opportunities, in existing programs where feasible, or in special programs as needed; camps; parent counseling and homemaker services; opportunities for religious participation."

At the same White House Conference it was recommended "that community facilities for diagnosis and identification be readily accessible to anyone suspected of a mental handicap; provide integrated diagnostic study involving all necessary professional skills; provide counseling, including parent-to-parent counseling where appropriate, as an integral part of the service; direct special attention to the needs of rural areas." (590) 2/

So far as can be determined, the last phase is the only reference in the 1960 White House Conference forum Recommendations to problems facing the mentally retarded in rural areas. The challenges ahead, the rehabilitation of those rural youths and adults determined to be mentally retarded, requires the best thinking, careful planning and wise action on the part of all. No one can claim a monopoly on service. However, one can admit to a common need, to a public responsibility, to the urging for a united all out attack on mental retardation.

Instead of thinking of the mentally retarded as mild, moderate or severe or as morons, imbeciles or idiots, or as one with an I.Q. of 75, 50 ,or 25, or as educable, trainable or untrainable or as marginal-independent, semi-dependent or dependent, consider for a moment, the person who is mentally retarded. Rather than use different terms which mainly classify, but do not say much and may even retard efforts to think clearly about the problems, consider the individual. Describe what his needs may be; think about how best to meet his needs. Consider what programs and services may be required to enable such persons to assume citizenship responsibility. Focus on the person who is retarded. Think of him as a family member. Consider the relationship and responsibility of the family to the rehabilitation process. Take a look at the community and neighborhood where such a handicapped family resides.

EXAMPLES OF PROGRAMS

In order to obtain a "grass roots" response to the subject at hand it seemed a wise move to go directly to rural America, to the states where the problems exist. A one page letter went to 30 states previously visited by the author. Each person receiving the letter was asked to reply to the question "In what way do you believe retarded youth in rural parts of your State will best be prepared for gainful employment? Support your statement with an ideal program operating, or needed, or planned. Sheltered employment as well as competitive gainful employment are to be considered of equal importance."

As of mid-July, 19 states and the District of Columbia had responded. What was said? What information was provided? What suggestions were offered?

From West Virginia "...The best approach would be the establishment of sheltered workshops in the more populated areas with dormitory facilities. Another alternative would be to train the mentally retarded from rural areas in centers in occupations found in rural areas, i.e. dairy husbandry, shoe repair, gardening, dairy farming."

From Washington, D. C. "...encourage parents to place their children in training situations...identify certain small town or rural jobs that could well be performed by qualified retarded persons...workshops with half-way house living accommodations are essential..."

Tennessee states "...We are attempting to solve the problem through vocational training centers for mentally retarded adults and other handicapped people in the non metropolitan counties, whose population ranges from 12,000 to 60,000..."

From South Dakota..."The only answer is a by-the-week residential center located in the area to provide a total program...on-going sheltered workshops could serve more retarded persons in the rural areas if residential centers near these shops were available..."

California reports..."There can be several approaches to prepare retarded youth in rural America for employment, among these, greater use of 4H Clubs, homemaker services for retarded females and farm and craft work for retarded males...better location of rehabilitation counselors in rural parts of the states would help..."

Texas feels..."Our two agricultural-ranch type workshops with residential units appear to be working out very well in Austin, Texas and in the Rio Grande Valley..."

Hawaii states..."Though not rural they believe in sheltered workshops at this time which seem to be satisfactory..."

Louisiana believes in "a coordinated approach through proper legislation ...regional centers is the key word."

Georgia believes that through..."an expansion of the vocational rehabilitation program as it is currently operating the problem will be lessened considerably.

The state of Washington recommends..."start early in the life of the retarded and provide a full range of programs and services so that at age 18 or so the retarded person will be ready for work...supervised work centers need further exploration. Crews of such workers have received emergency calls for harvesting of early-ripening crops, planting of trees etc."

North Carolina believes that..."if we can get vocational training centers and some type of workshops in as many areas as is possible so that they are easily accessible to the total population this would be ideal..."

Delaware wants to see "more sheltered workshops, more opportunities for retardates to get drivers' licenses, and live in - industries..."

Virginia likes to see "sheltered employment on an individual basis in such areas like farming, nursery work or in small industry...more parent participation is essential for any program to succeed...."

Missouri believes that a "three level shop would do the trick -- one level for evaluation, work adjustment and a varied training program aimed toward placement; a middle level for those needing sheltered jobs and a third level for those requiring day care services..."

Michigan states that ... "a move is on to have smaller school districts ... greater use of the University Farm or Home Extension Services for training retarded youth ... for the girls ... training for cannery work ... for the boys

state and national forest jobs...the Domestic Peace Corps might work with 20 or some retarded in a small group living plan working as pickers."

Minnesota believes in a..."combination of adequate preparatory services for them must exist along with a high level of professional and parental concern..."

Iowa would like to have..."the development of facilities start in a logical order with activity programs as well as workshops in the network of services operating..."

South Carolina reports..."more emphasis on vocational training and less on academics is essential for success...they recommend specific job training be provided like mill work, yard work, nursery jobs and homemaker training... we should start early in the life of the retardates...in the home, pre-school programs, day care service, public school classes, etc..."

New Mexico would like to see..."selected job training for non-automated jobs...more adequate transportation...regulated stoop labor in such jobs like poultry production, laundry work, cooking, dorm work, crop packaging, etc..."

New Hampshire would like to see..."more facilities, greater transportation and more public support of essential programs..."

In review, three recommendations stand out: transportation, facilities with some residential feature, qualified staff to man the programs. Transportation problems conceivably might be lessened were facilities established with live-in features. However, where this is not desirable or feasible, transportation looms up as a crucial problem if rural youth are to attend much less return from available facilities.

RECOMMENDATIONS

Moreover, generally more retarded individuals have greater needs for transportation. One possible solution to this problem might be rehabilitation mobile units similarly constructed like the travelling library or X-ray units. Mobile units for retarded youth could schedule visitations to rural parts of a state in advance and with properly staffed vehicles could provide case-finding evaluations and some vocational interviewing or training.

Regional centers might be a partial answer in other instances. In such centers staff persons could carefully evaluate and train persons from some of the outlying areas. When facilities and staff persons are in short supply, the regional center that is adequately financed and properly located seems to offer some solution to the staffing problem.

Informal residential units are thought to be those live-in settings, dorms and the like for short-stay purposes. Upon completion of evaluation or training, persons would be expected to leave for other living quarters. In some instances such live-in arrangements can be rehabilitation oriented as they are in some states with the focus on teaching the resident how to live in the residence so that when he leaves he can do the same thing elsewhere.

There needs to be a more creative use of existing facilities around the nation. Too often one group of handicapped are in dire need of a facility, require services of one sort or another while in the same community there are available facilities which lack sufficient people to serve. In a number of instances retarded persons can be served in other facilities which ordinarily do not serve them. This requires further study and review and should receive some priority during this Conference. Communities cannot afford to waste human resources in this fashion. It seems far more challenging to create new programs rather than attempt to reclaim previously unserved persons.

Voluntary and governmental resources are needed of a variety of types. Voluntary programs demand a more stable financial base if they are to operate successfully. While it is important at times for Federal monies to be used to start or expand a voluntary agency program, local communities have to reevaluate their readiness and need to continue their financial support. In addition, more Federally-established facilities need to be opened around the nation to reduce the backlog of huge caseloads everywhere.

The argument still continues - generalist or specialist. By and large the answer tends to be that the more retarded the person may be, the greater the need exists for a specialist. On the other hand, the less retarded a person may be, the more need exists for a generalist. Others feel that generalists tend to become specialists by nature of the fact that they face numbers of situations where other professional persons are unavailable. In these instances, the generalist becomes more specialized in the other areas to do his job better. Training programs that prepare professional persons for work in rural America might find it desirable to have the generalist become more acquainted with the specialist and the opposite.

A number of pilot projects appear essential if the task ahead is ever to become manageable, much less properly handled. Some of the new ideas that might be tried out appear in the comments previously given by the states enumerated. Few of these suggestions have been documented, validated or replicated. The field is wide open for good projects in this area of work.

The President's Proposed Program for National Action to Combat Mental Retardation lists nearly 100 major recommendations. Several of these recommendations bear on the subject at hand. For example, it is recommended that (1) Sheltered work opportunities for the mentally retarded should be extended beyond the traditional workshop setting. 3/ It is suggested that such activities might include conservation and maintenance of parks, recreational areas and grounds of public institutions, domestic service occupations, certain types of health service, and agricultural occupations. (2) Every effort must be made and all available services used to equip and train the retarded and assist them in finding suitable employment. 4/ (3) Methods of providing recreational and therapeutic activity centers to serve severely handicapped adults should be explored. 5/ It is suggested that goals less than full employment for the retarded may be equally essential and suitable evaluation and training programs for this purpose ought to be established.

There has been some thought given to the need for a Rural Peace Corps rather than a Domestic Peace Corps. The problems that retarded persons face in rural America are generally the same as those retarded youth face in non-rural areas of the nation. However, as indicated earlier in this paper, without transportation, proper facilities of a partial residential nature and suitable staffing of such facilities, not much is going to happen to assist the retarded youth in rural parts of the nation. It would seem that a rural peace corps would answer, in part, all of these three major problem areas: (1) A motor corps could be established by a rural peace corps group who could transport retarded youth to and from essential programs and services. (2) A rural peace corps could help construct, alter or repair buildings to make them more suitable for training purposes indicated. (3) A rural peace corps could be trained just like the original Peace Corps group is trained and be assigned to man some of facilities needed to rehabilitate or properly train retarded rural youth for work.

In a number of instances the rural peace corps would find the challenge great and the rewards equal to the effort.

CONCLUSION

In the deliberations at this National Conference no one can forget to think about the fact that at the current rate of incidence and prevalence, a retarded child is born every five minutes. Such retarded children born in our lifetime have every right when adults to equal education, rehabilitation and employment opportunities as other Americans.

Fortunately, there is a more positive attitude in the nation, "that the retarded adult is a useful person and can help himself more than was ever known possible before." This has been bolstered by the President's Panel Report, his Message to Congress and his continued emphasis on equal opportunities for the mentally retarded. 6/

There are other problems yet to be overcome before the bold new approach everyone is waiting for will occur. One of these is the proper utilization of available information already acquired. Another is learning how to help this group attain employment and work well with employers and other workers. There is still a major concern on the general inability of local communities to adequately financially support essential programs of direct help that increase the employability of the mentally retarded. Finally, research results rarely are applied where they might do the most good. Too often they are shelved, gather dust somewhere or appear in the literature. Not enough action-research of a short term nature is available nor are such studies properly transmitted to others when completed for instant use to help the group being studied.

Everything considered, the retarded rural youth of America stand on the brink of great expectations. Without question, whatever can be done to further their employability will strengthen all of America.

FOOTNOTES

1. Conference Proceedings
Golden Anniversary White House Conference on Children and Youth, March 27 to April 2, 1960, Wash., D. C., The Multiple Handicapped, Resolution 582, P. 386.

2. Ibid.,P. 387.

3. A Proposed Program For National Action to Combat Mental Retardation, The President's Panel on Mental Retardation, October 1962, P. 122, U. S. Govt. Prihting Office.

4. Ibid.,P. 129.

5. Ibid.,P. 123.

6. Message from the President of the United States Relative to Mental Illness and Mental Retardation, 88th Congress, 1st Session, Feb. 5, 1963.
Guide to Job Placement of the Mentally Retarded, Words from the President, Publication of the President's Committee on Employment of the Handicapped, 1963, U. S. Govt. Printing Office.